AUTUMN 2009 ISSUE 229 THE MAGAZINE OF THE association for spina bifida hydrocephalus ability beyond disability™

link

Television first for David

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Christmas Cards

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Each pack of 10 cards and envelopes comes with a greeting inside each card that reads: With all Good Wishes for Christmas and the New Year.

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Starlit night

Sprout

The Holy Infant

Three wise sheep

Robin and berries

Plaice mats

Dove

Lights

Santa

Snowman

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ASBAH, 42 Park Road,
Peterborough PE1 2UQ

Registered charity no. 249338

It's hard to believe it's autumn already and time to be thinking about Christmas! But as you'll see opposite, our Christmas cards are in and ready to order - with five new designs added to the range to choose from.

I'm writing this just after our AGM where we launched an exciting new initiative to encourage all our members to get active, improve fitness and enjoy sport - from beginners to paralympians – and all mere mortals in between. You can read more about 'Fit for Success' on page 11 and on our website.

Our special feature this issue looks at how hydrocephalus can impact on self-esteem, social and learning skills and how to deal with these effects. The personal stories from our readers are very encouraging and show how they have not let hydrocephalus stop them from getting on and enjoying life.

If there are topics you would like to see covered in future issues we'd be delighted to hear from you. Please get in touch by phone, email, letter or fax and let us have your views.

Gill Winfield

Gill Winfield
Editor
email: gillw@asbah.org

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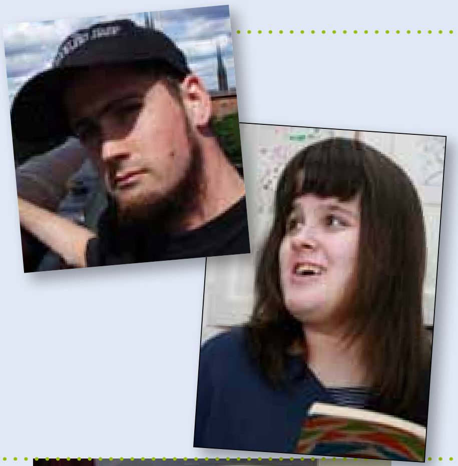


Report investigates getting children back to sleep

Researchers at York University have been investigating the effectiveness of behavioural approaches to the management of sleep problems among disabled children.

The project, run by the University's Social Policy Research Unit, was funded by the Centre for Excellence and Outcomes in Children and Young People's Services.

The researchers carried out two rapid reviews looking at what works best in training parents to manage sleep problems. A concurrent study looked at ways of dealing with behaviour problems.

Information officer Rachel Pitman said: "Sleep problems are common and persistent in disabled children and have a number of effects on the child and family.

For parents, they are associated with high levels of stress and irritability while for children they are associated with poor concentration and increased probability of daytime behaviour problems.

"However, only a minority of families who have a disabled child with a severe sleep problem appear to receive help in dealing with the problem."

The research project, carried out by Catriona McDaid and Patricia Sloper, reported that these problems are very persistent and are not likely to disappear without intervention.

Children with sleep problems may cry or shout out when they wake and elicit a response from parents, which acts as a reward. Intervention is aimed at the child learning to go back to sleep without parental attention.

The high prevalence of sleep problems in disabled children can be caused by physical and medical conditions associated with disability. Problems in learning may hinder the establishment of appropriate routines for settling and staying asleep.

The report concluded: there is sufficient evidence that providing parents, of children with severe learning disabilities, with information and/or individual treatment plans on behavioural techniques for dealing with sleep problems are promising approaches.

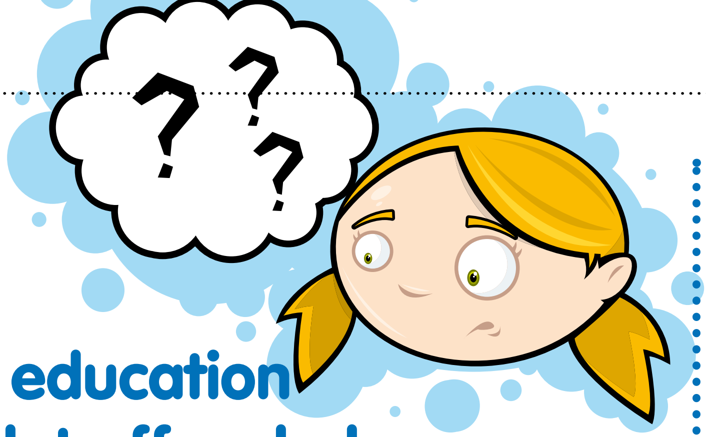
Sleep help on hand

The Cerebra charity was set up to help improve the lives of children with brain-related conditions.

It offers the parents of disabled children information, support and a variety of services - including advice on solving sleep problems.

Its Sleep Service provides assistance with a range of sleep issues for families, and staff can give advice by telephone, post, home visits or email.

For more information visit its website ***www.cerebra.org.uk*** or call the Parent Support Line on 0800 328 1159.



New education booklet offers help

If your child finds some areas of learning difficult, a new booklet .produced for ASBAH for young people with hydrocephalus, could help them with their school work.

Although the A5 publication, Hydrocephalus and Learning, is aimed primarily at children during their middle school years, it is packed with tips and advice that others may find useful too.

The booklet, produced with input from ASBAH's education advisers and Dr Sophie Thomas, a Clinical Psychologist in Paediatric Neuropsychology, explains to children with the condition why they can have problems with learning and how hydrocephalus may affect them.

Topics covered include:

- **Memory** – and tips on how to make it easier to remember things.
- **Processing speed** – why it can be hard to take in lots of information in one go and actions to take to keep up.
- **Concentrating** – why it can be difficult and how to make it easier.
- **Planning and organising** – often a problem for anyone with hydrocephalus, and tips to improve.
- **Spatial awareness** – why there may be difficulties with this and ways to improve it.
- **Getting on with teachers** – how to give teachers information about hydrocephalus which will help them to help their pupils.

Hydrocephalus and Learning will be available this autumn priced £3 inc p+p. To order your copy contact ASBAH's Helpline 0845 450 7755.

New group offers IIH support

A new organisation is offering support to people who have Idiopathic Intracranial Hypertension (IIH).

IIH, a neurological condition of high pressure of the fluid around the brain, is also known as benign intracranial hypertension (BIH), although this term is falling out of use.

IIH UK, which was established in August 2008, was set up by people with the condition to offer support and information to others.

IIH UK's website is a useful source of information with downloadable leaflets and links to other information sources.

The website also has a forum where you can meet other people with IIH, share your experiences and learn about how others live with this condition.

For more information about IIH UK go to its website at ***www.iih.org.uk*** or write to: IIH UK, 31 Wellington Street, St Johns, Blackburn. Lancashire. BB1 8AF

Please note, the IIH UK site and the IIH Support forums are run by volunteers who are not medically trained. They cannot answer medical questions or legal questions or provide individual email support.

Swine flu

If anyone has any concerns regarding Swine Flu, in children or adults with spina bifida or hydrocephalus, they should contact their GP for each case to be considered on an individual basis.

If we receive any specific information from the Department of Health this will be passed to our Helpline and advisers, and will be available from ASBAH's website.

Guide for new parents now available

A guide to parenting, for people who only have the use of one hand, is now available.

Although the title suggests the guide is only for one-handed parents, topics covered will also be helpful to any new parent who has difficulty in using both hands. The guide may also be useful for health professionals supporting disabled parents.

One-handed parenting is published by Disability, Pregnancy and Parenthood International (DPPi) a small, UK based charity, managed by disabled parents, which promotes better awareness and support for disabled people during pregnancy and parenting.

The guide provides information on various aspects of baby care, including daily tasks such as lifting and carrying, nappy changing and feeding your baby. The reassuring, practical guide also has sections on travelling with your baby, safety at home, bathing and bedtime.

For each subject area there are user-friendly ideas for equipment that could be used and suggestions for points that should be considered when going about tasks.

The booklet has a comprehensive list of useful publications. Suppliers of equipment mentioned in the guide and the names and addresses of other organisations that could provide advice and support to new parents are also provided.

For copies of the guide, please contact DPPi on 0800 018 4730 or email *info@dppi.org.uk*

Can you contribute to our Young ASBAH website?

We are developing our Young ASBAH website and hope to make it lively and appealing for 12 -18 year olds who have hydrocephalus or spina bifida.

The site, based on an original pilot site for those in the Liverpool area, will feature information about spina bifida and hydrocephalus plus lots of other information relevant to teenagers.

We're hoping that our teenage readers will have an input to make it as bright as possible.

We're looking for book, film and music reviews, links to websites you use, personal stories and articles on any topic that you think other young people will enjoy. The information can be about anything... it doesn't have to be disability related.

The material we have already put together includes items about bullying, keeping safe, moving towards independence and sport and leisure opportunities.

Like the Your Voice site for adults, Young ASBAH will feature a variety of information on living with spina bifida and hydrocephalus, health advice, how to contact ASBAH for help and useful links to other websites.

I hope many of our young service users will be interested in sending in material which will be of interest to other teenagers

Gill Winfield, Marketing and Communications Manager said: "I hope many of our young readers will be interested in sending in material which will be of interest to other teenagers.

"Our youth website has great potential and the more contributions we get, the better it will be."

If you would like to contribute to ASBAH's new youth website send in your ideas, articles etc to *gillw@asbah.org*

Caring youngster nominated for award

Young Alice Rush has been nominated for an award for her work helping injured birds of prey.

Alice,11, from Wilburton, Cambridgeshire, is one of five children from the Junior Raptor Club who have been short-listed for an award to honour young people's exceptional contribution to the community.

Alice, who has spina bifida and is one of the youngest members of the club, has been caring for the injured birds for the past five years.

She said: "I enjoy Junior Raptors so much because I get close to the birds and can see what they do."

Liz Blows, Chief Executive of the awards, said: "Alice is not only the youngest nominee, but does not let the conditions of spina bifida and hydrocephalus stand in the way of her volunteer work at the foundation."

Alice's mum Vicki told *Link*: "Alice loves the club because she gets to spend time outdoors with the birds. Her membership has made a huge difference to her life."

unique
Insurance as individual as you

We've added Unique Insurance to our list of partners, to offer Link readers a range of insurance products, including: travel, life protection, motor and home insurance policies. This specialist insurance scheme is designed for people with spina bifida or hydrocephalus, their friends, family, carers, and supporters of ASBAH. For every policy purchased they will make a donation to ASBAH - at no additional cost.

For the full range of products, see ASBAH Online offers at: www.asbah.org or contact Unique: 01603 828 239 Email: Unique@heathlambert.com

Befriending service can help

Coming to terms with your child's disability can take time and talking to another parent who understands what you are going through can help you face the future.

The Face 2 Face charity is a one-to-one befriending service for parents of disabled children, offering emotional and practical support.

Its network of trained volunteer befrienders can help parents make positive adjustments to the news that their child has a disability.

Every Face 2 Face befriender is a parent too – someone whose own child has a disability. They know what it's like to cope with a new diagnosis and can offer support parent-to-parent.

The service, available in some areas, is free and confidential. A befriender can either visit you at home or you can agree another convenient location. If the service isn't available in your area you can access the online befriending service.

Tommy's Mum Ruth said: "Face 2 Face put me in touch with Pauline. She answered my questions and made me see there was a way forward, and that I was not helpless – there was so much I could do."

The charity also offers training for parents who would like to become befrienders and a telephone sleep advice line and active intervention with trained counsellors.

To contact Face 2 Face call 0844 800 9189 or email face2facenetwork@scope.org.uk Check out the website at *www.face2facenetwork.org.uk*

Society for Research Into Hydrocephalus and Spina Bifida

This year, the 53rd Society for Research into Hydrocephalus and Spina Bifida (SRHSB) meeting was held at Queen's University, Belfast.

The pre-meeting scientific session included research into a method of repairing myelomeningocele, which could prevent the complication of tethered cord; and the possible link between neuropathological effects of hydrocephalus with perceptual problems later on.

left to right: Marie McConnell, Geraldine Long, Jenny Green and Jackie Bland

Gill Yaz and Rosemary Batchelor

In the main meeting, various papers looked at methods of bowel and bladder management – eg comparing Peristeen anal irrigation system, with ACE (antegrade continence enema). Another compared the amount of support needed by parents of children using these two methods.

The special lectures included one on a UK neurosurgeon's view of pain management.

Also from the UK, was a poster, presented by Marie McGonnell, ASBAH Health Adviser, on "Changing needs for children with spina bifida and hydrocephalus in Northern Ireland", and a paper on an ASBAH-funded study on cognition in hydrocephalus.

The new President is Dr Roger Bayston from Nottingham, who is also Chair of ASBAH's Medical Advisory Committee.

Gill Yaz, Paula Thompson and Rosemary Batchelor would like to thank Coloplast for the educational grant which allowed us to attend this meeting.

Rosemary Batchelor
Senior Health Adviser, ASBAH

Two of ASBAH's West Midlands advisers, Geraldine Long and Jenny Green, gave a presentation at the SRHSB outlining their research into the effects of ageing on the health of people with spina bifida and/or hydrocephalus. You can read more about this and the full research report 'Journey into the Unknown' at *www.asbah.org*

For more information on the SRHSB meeting and the study into the effects of ageing please visit www.asbah.org

Ongoing research provides mothers-to-be with vital information

Our ongoing research project into in-utero Magnetic Resonance Imaging (MRI) has provided mothers-to-be with improved diagnosis of fetal spine and brain abnormalities.

The research study, headed by Professor of Radiology, Paul Griffiths, is now in its fifth year.

Since the launch of the study, local associations and ASBAH area advisers have recruited 75 pregnant women whose unborn baby has been diagnosed with spina bifida.

Professor Griffiths and his team, at Sheffield's Hallamshire Hospital, have carried out in-utero MRI since 1999. All of the women scanned have been in their 20 – 24th week of pregnancy.

His studies have revealed that, in most cases of spine and brain abnormalities, MRI provides vital, detailed information.

The team's work has shown a 48 per cent improvement in diagnostic accuracy in detecting fetal brain problems using MRI compared to ultrasonography.

Professor Griffiths said: "In 2004 we were awarded a grant for £20,485 by ASBAH to look at 20 pregnant women whose unborn babies have neural tube defects."

With ASBAH's help with recruitment and further fundraising, the study has been extended to include 75 women, and is still ongoing. "Our research has pushed forward MRI techniques to provide far more information for pregnant mothers," Professor Griffiths added.

After securing additional funding, ASBAH has been able to give Professor Griffiths the go-ahead on further research studies.

Professor Griffiths said: "More recently we have been awarded £13,125 to study the clinical effects of fetal ventriculomegaly diagnosed in-utero by MRI scanning. That study has just started to recruit."

The project is also assessing children for the clinical significance of mild and moderate fetal ventriculomegaly.

ASBAH research project helped us

Lorna Korbel from East London was offered the chance to have an in- utero MRI scan when the baby she was carrying was diagnosed with spina bifida and possible brain damage. Here she tells her story....

"We were told at a 22-week scan that Evie had spina bifida and hydrocephalus, with a possibility that she was severely brain damaged. It was a massive blow. Neither of us could stop crying and we didn't know where to turn.

My midwife suggested I called ASBAH but at that stage I didn't really want to talk to anyone.

The lady was so lovely and put us in touch with our adviser who visited us and gave us so much support. Without her I don't know what we would have done. She also arranged for me to be scanned by Professor Griffiths' team in Sheffield.

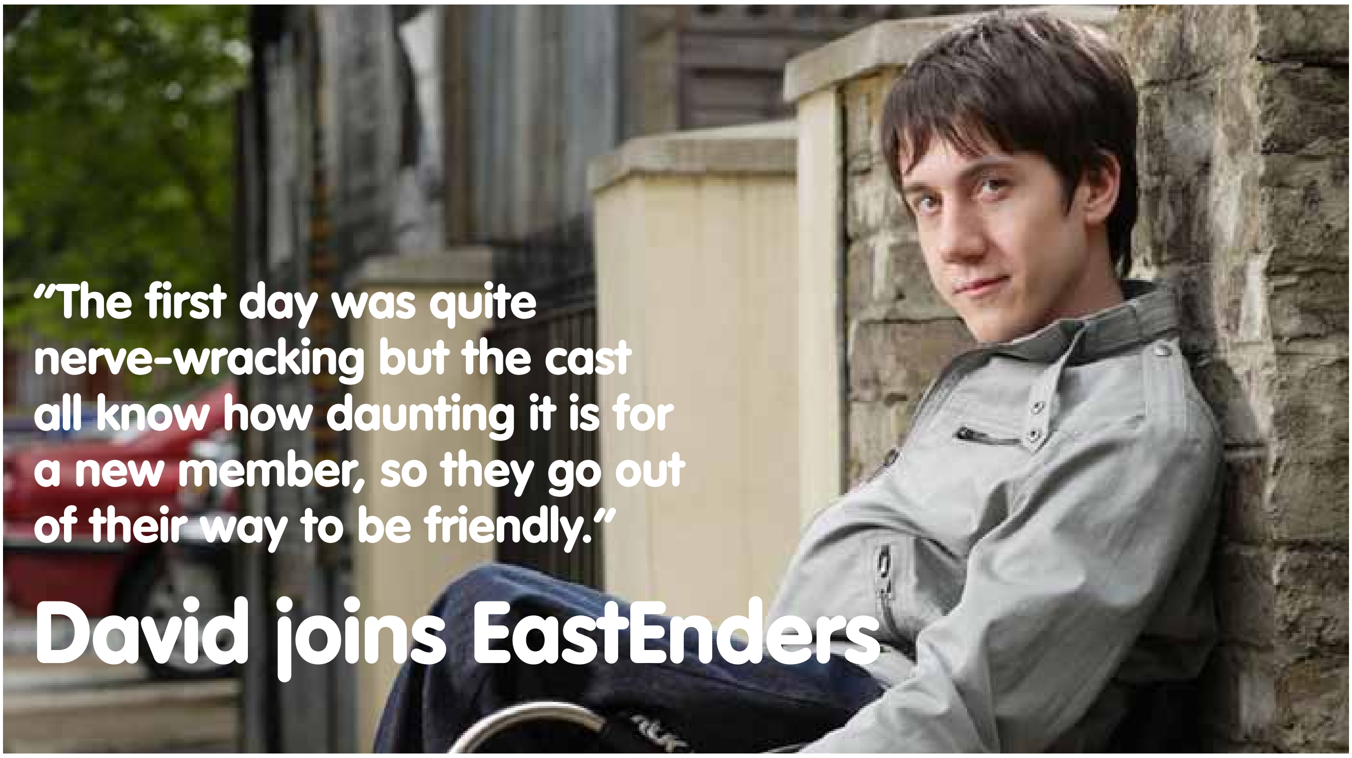
I had the scan and we were told that they were 99.9 per cent sure that Evie had no brain damage. The relief was indescribable.

Evie was born six weeks early and to us she is absolutely perfect in ever way. She had a shunt inserted at three weeks and several weeks later had her feet rectified.

I sometimes wonder what we would have done if it hadn't been for ASBAH."

Read more of Lorna's story at www.asbah.org

David joins EastEnders



"The first day was quite nerve-wracking but the cast all know how daunting it is for a new member, so they go out of their way to be friendly."

Talented young actor David Proud has hit the headlines after winning a coveted role in EastEnders.

David, 26, who has spina bifida, made his screen debut in September, playing the part of Adam Best, an Oxford University student who arrives in Walford to visit his mother, Manda (played by Josie Lawrence).

It's a ground-breaking move for the popular soap as David, a wheelchair-user, will be the first disabled actor to have a regular part on the show.

The role of Adam is a dream come true for David, an ASBAH patron who first got a taste for acting three years ago after playing the lead character in the ground-breaking children's BBC TV programme, Desperadoes.

Many of the characters in Desperadoes were played by untried actors, recruited from real life wheelchair basketball teams.

After filming finished, David quit his day job at Peterborough's Job Centre and signed up with an acting agency, determined to give it his best shot.

And after winning several smaller roles including parts in ITV2's Secret Diary of a Call Girl and the feature film, Special People, he auditioned for EastEnders.

David said: "I'm used to auditions and I know the process, but I was still very nervous, especially for the recall.

"I was thrilled when I received the call offering me the part, although it didn't seem real until the press release went out."

> **What is so refreshing is that Adam isn't a stereotypical disabled person. He has a lot of history and the script looks beyond the disability.**

He said that the character he plays is an interesting one. "Adam has been described as being 'irritating', but I prefer to call him spiky," David explained. "His attitude changes according to the company he keeps, so it's a challenging role."

When *Link* spoke to David he had been filming for five weeks and was settling into his new life on set.

"Everyone, without exception, has been very supportive, so I relaxed very quickly."

And while David has received his share of fan mail in recent years, joining EastEnders means a higher public profile.

"Before I even began filming I received a lot of letters from well wishers who are fans of the show," he said.

"EastEnders attracts around 8 million viewers and even those who say they don't watch the programme are aware of it.

"Other cast members have been advising me on how to handle the attention, and even my parents have been affected. My Mum works in a school so of course the pupils are always asking her questions."

EastEnders Executive Producer, Diederick Santer said: "I'm delighted to welcome David to EastEnders. He's a fine young actor with a wonderfully dry comic delivery, playing an interesting, and possibly rather irritating, character."

He continued: "I'm sure he, and his character Adam, will be strong additions to EastEnders."

left to right: Iain Crighton meets Gobi Ranganathan

Sam Bradley

Michael Jones

Danny Mills launches Fit for Success

Courtesy of Peterborough Evening Telegraph

Fit for Success!

An exciting new scheme to help people with spina bifida and/or hydrocephalus make the best of their health and fitness has been launched by ASBAH.

Fit for Success! was unveiled at September's AGM at Peterborough United football ground by ASBAH Patron, Danny Mills. He was joined by ASBAH's new Patron, EastEnders actor, David Proud, who has spina bifida.

The campaign is also backed by a host of paralympians and top-level athletes.

ASBAH Chief Executive Jackie Bland said: "Staying fit and healthy is one way of getting the best out of life when living with spina bifida and/or hydrocephalus. Many people with these conditions achieve outstanding success as athletes.

"We want to support all those people with spina bifida/hydrocephalus who want to achieve more in terms of their health and fitness - from small changes such as eating a healthier diet to training for a major event.

"And we want to make sure that ASBAH is there all the way cheering on our 2012 paralympians."

Fit for Success! has three main aims:

- **Supporting high-profile athletes to overcome any barriers they may encounter.**
- **Encouraging and supporting more people with spina bifida/hydrocephalus to engage with sport and physical activity and achieve personal goals.**
- **Promoting physical activity and good health throughout ASBAH's membership.**

As the project develops Fit for Success! will:

- **Gather information and statistics on the health and fitness needs of people with spina bifida and hydrocephalus, to discover which fitness regimes work best and making sure more people can access them.**
- **ASBAH's advisers will offer health and fitness advice to individuals, introduce them to different sporting/fitness activities and help people to identify personal goals.**
- **Keep in close touch with athletes and players, providing or identifying support where necessary and providing grants to help individuals.**
- **Work in partnership with other providers to help them understand the health and fitness needs of people with SB/H.**
- **Organise meetings and events which introduce people to sport/fitness/health activities and provide support.**

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Already backing Fit for Success:

Danny Mills, ASBAH Patron and former England and Manchester City defender.

Pippa Britton, paralympic archer

Louis Smith, Beijing Olympic medal winner (gymnast)

Gobi Ranganathan the UK's no.1 disabled badminton player

Sam Bradley (swimmer - Paralympic 2012 hopeful)

Christopher Maw (wheelchair racer - Paralympic 2012 hopeful)

Louise Hunt , wheelchair tennis player - Paralympic 2012 hopeful)

Gobi nets more medals

Former national gold medal swimmer, Gobi Ranganathan turned his attention to badminton after retiring from competitive swimming and is now one of the country's most successful wheelchair athletes.

Gobi, 33, is Britain's number one wheelchair badminton player, retaining his Four Nations men's singles title four times, and winning the men's doubles on three occasions.

He competed in the German International in Dortmund in May, which attracted more than 100 competitors from 17 nations.

> **I had played a little badminton socially with friends before, but within a few months was entered to take part in the Four Nations championships in Cardiff**

Gobi, who has spina bifida, said: "I competed in Singles, Mixed Doubles and Level Doubles and had varying degrees of success in each. I didn't get through the group stages in either of the doubles events but won Bronze in the Singles after getting to the semi-finals."

"Unfortunately badminton is not yet a Paralympic sport," he explained. But while he can't aim for Paralympic gold in 2012, Gobi, a highways engineer from Stevenage, is determined to retain his position at the top.

"It all started when I was asked to join a wheelchair badminton club," he said. "I had played a little badminton socially with friends before, but within a few months was entered to take part in the Four Nations championships in Cardiff.

"Last May I competed in the European Disabled Badminton Championships in Dortmund, Germany, representing England in the men's singles, doubles and mixed doubles events.

"The tournament was a baptism of fire as I was drawn against the world number one, Quincy Michielsen of Holland. Although I didn't win, playing against Quincy was a huge experience."

Gobi has now acquired a taste for international competition and is keen to compete at this higher level and is currently, with the help of the Badminton England organisation, seeking sponsorship to help cover his costs.

He told *Link*: "Coming home from a competition as gold medallist is a great feeling and has given me the drive to win more," he said.

New challenges for Ann

Five-times paralympian, Ann Wild has bowed out of the world of international wheelchair basketball, retiring at the top of her game.

Ann, from Ilford in east London, took the tough decision after being affected by a serious wrist injury.

She said: “It was always going to be an incredibly difficult decision, but following my injury the time seemed right. I received treatment alongside Paula Radcliffe at the Olympic Medical Institute but it takes a long time to recover from an injury like that.”

> **I wish all the people looking to compete in London 2012 the best of luck and my advice is always to follow your dream.**

The renowned athlete, who has spina bifida, competed at her sport for an incredible 24 years, but doesn’t intend to take things easy now.

Instead she has taken up rowing and can regularly be seen training with a former GB coach at the London Regatta Training Centre in Docklands.

And while she says “it’s early days yet,” Ann is certainly a name to watch out for. She hopes to return to international competition in the sport and said: “I don’t know about future Paralympic Games, but maybe.”

She will also continue to coach youngsters from the age of four and upwards who are aiming to be the wheelchair basketball stars of the future.

Ann, who also assists with the personal training of Great Britain athletes, told *Link*: “I have always tried to give as much back to the sport as I have taken out and to help the development of wheelchair basketball in this country.”

Ann, 36, captained the national women’s wheelchair basketball team for 15 years after making her international début aged just 13.

She said that she never let her disability hold her back and got involved in a number of sports from a young age.

“But when I was 13 I really had to decide what my specialism would be. When I was selected for the Paralympics in Seoul the decision was really made easy.

“Now looking back I can’t believe what I achieved during my career. When I consider that I took part in five Paralympics it all seems a bit unreal.”

But an enviable collection of medals and awards confirm her outstanding contribution to the sport.

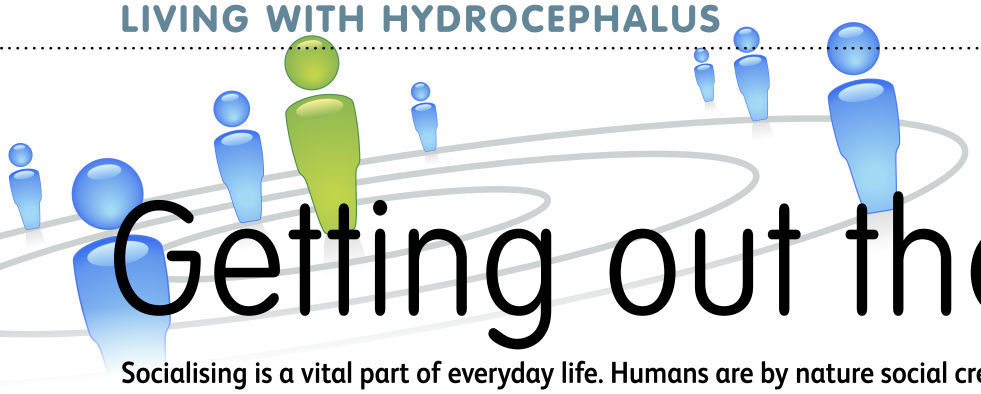
Honoured as a “legend of the game” by the International Wheelchair Basketball Federation, Ann was also voted Most Valuable Player in Europe, in the 2003 European championships.

In 2004 and 2009 she received Outstanding Achievement Awards from Brunel University - where she graduated in occupational therapy - following her performance at Athens 2004 and Beijing 2008.

“The Paralympics is such a special event,” Ann added. “Every one I competed in holds wonderful memories for me.”

Visit Ann’s website at ***www.annwild.co.uk***

Ann Wild meets Tanni Grey-Thompson



Getting out there

Socialising is a vital part of everyday life. Humans are by nature social creatures and we all need to meet new people and make friends, whether for work or for pleasure. Not everyone finds it easy to meet new people, but like most things, the more you do it, the easier it becomes. Gaining one new friend makes you feel good about yourself and you're more inclined to meet others.

Out and about

You won't meet many new people if you stay indoors.

- Find out about clubs in your area and don't restrict yourself to groups for disabled people. Libraries and newspapers are a good source of information.
- Check out local colleges for courses. Perhaps you have always fancied trying your hand at jewellery making or photography? Why not bite the bullet and sign up?
- The facilities at sports centres are becoming more accessible. Give them a call and see what's on offer.
- Consider voluntary work – it's the perfect way to meet people, get out in the workplace and boost your confidence.

Self-confidence

Self-confidence is a precious commodity. If you have it, the world is an easier place – you trust your abilities and judgement and will find it easier to meet people and make friends.

Without it, you can be insecure and hesitant, nervous of putting yourself in new situations and overly concerned about what others think of you.

But confidence is something that you can build on in lots of different ways.

- Focus on the positive - identify areas you are confident in and analyse how you achieved that confidence.
- Keep busy – having too much spare time is demoralising.
- Make the most of yourself – wearing nice clothes and a good hair cut all help to build confidence.
- Taking up a sport or activity can help with low self-esteem.

Online safety

- Social networking can be a lot of fun but users need to consider their safety.
- NEVER give personal information to anyone you have not met in person. If someone presses you for this type of information, back away.
- If you feel you just must meet a new online acquaintance, NEVER go alone, and ALWAYS meet in a very public place like a popular coffee shop.
- If you are under the age of 18 NEVER meet up with someone you have only met online unless your parents agree to go along with you to the meeting.

Social networking

Some people consider them banal, but it has been proved that the internet's social networking sites can reduce loneliness and improve well being... but be warned, they can be addictive.

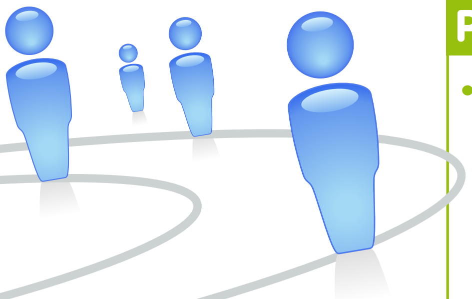
There are a whole host of them out there ranging from Facebook, Bebo, MySpace and Twitter. Dedicated sites for disabled people are springing up all the time too – check out ASBAH's Your Voice site which is specifically for adults with spina bifida or hydrocephalus at www.asbah.org/yourvoice.

You can keep in touch with people, post photographs, post messages and comments and find penpals.

Forums, message boards and chat rooms are also a good way of communicating – particularly if you have difficulty getting out and about.

Sites for disabled people include:

- *www.disabilityresourceexchange.com*
- *www.thewheellife.com*
- *www.Ablehere.com*



KEY POINT

- **Some ideas for socialising**

Gareth Starling

Gareth Starling has worked hard to make sure that having hydrocephalus does not limit his life.

He fell in love with riding as a young child, and when he began working with horses, had ambitions to become a jockey.

After GCSEs Gareth, now 28, attended Agriculture College where he studied for a diploma in horse care and then found work at a stables.

"From the age of 17 to 25 I worked with horses and my ambition was to be a jockey, said Gareth. Gareth eventually found a position at stables where the owner agreed to put him forward for his jockey medical - but Gareth failed on the grounds that he was unable to judge distance.

At another stables I worked at, I decided to keep quiet about having hydrocephalus. "It wasn't a problem until I had a fall. The staff said I was fine but I insisted on going to hospital for a check-up to make sure that my shunt hadn't been affected. Of course after that I wasn't allowed to ride there, so I moved on."

My Mum has always encouraged me to get on with things so that's what I did.

Gareth said his childhood was fairly normal and initially he attended mainstream schools.

"At college I was able to pick and choose friends who I could trust and I tried to explain to them early on what hydrocephalus was.

"When I met Fiona, now my wife, it was easier because she's a nurse and was familiar with the condition."

Today Gareth lives with Fiona in Leicester and works as a healthcare assistant at the local hospital.

"I enjoy my job, it's really interesting work. And of course working in a hospital environment means that having hydrocephalus isn't a problem."

To read more about Gareth's story please visit www.asbah.org

Christian Walmsley

Christian Walmsley may have hydrocephalus and cerebral palsy but he doesn't let that stop him getting on with his life.

Christian, 23, has worked for six years in the Eastbourne branch of McDonalds, has lived independently for the last three, and can handle most things himself... apart from his ironing, cleaning high shelves and changing light bulbs.

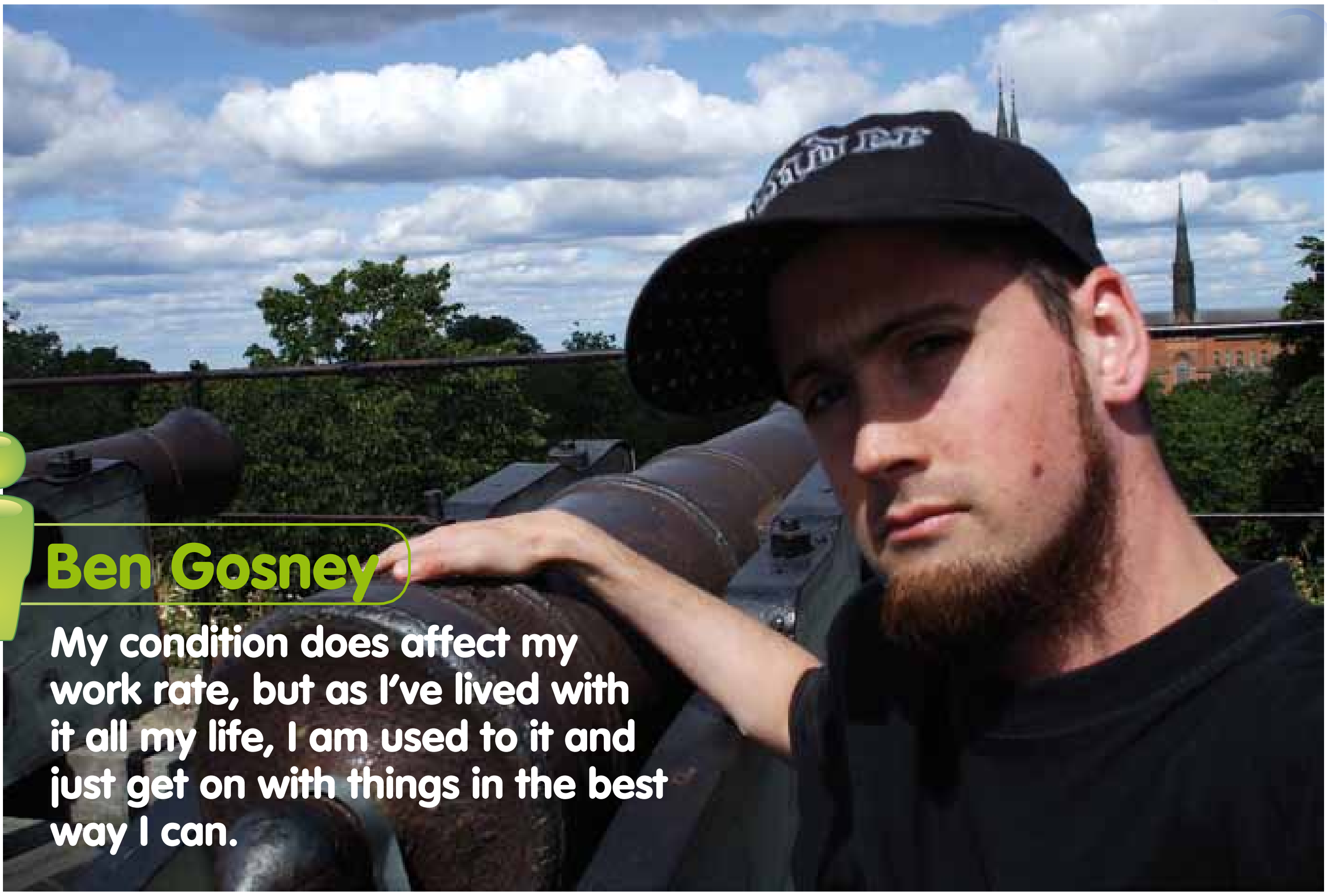
"I have always tried to get on with things myself," he said. If there is something I can't do I try to find a way round it. The right side of my body is weaker than the left so things like cleaning can be difficult and I can't do my ironing, but my Mum helps out with that."

But Christian admitted that until he became involved with Sussex ASBAH (SASBAH) several years ago, he struggled to make friends.

"I never felt very comfortable in social situations," he said. "It just didn't seem right and I would rather have been at home.

"Joining SASBAH really turned my life around. I was with people I could relax with and I have made a lot of friends. I go to the regular meetings and events such as bowling evenings and the residentials – it's a whole new life for me.

"I'm much happier in myself and I've gained confidence too. I now do volunteer work and am on the bank staff at the local hospital, which have also helped to boost my confidence."



Ben Gosney

My condition does affect my work rate, but as I’ve lived with it all my life, I am used to it and just get on with things in the best way I can.

PhD student Ben Gosney has found ways of coping with the symptoms of hydrocephalus to ensure his life runs as smoothly as possible.

Organisational skills and short-term memory are key areas affected by his hydrocephalus, along with reduced manual dexterity and frequent headaches.

> **I still find it difficult meeting new people and I tend to be fairly quiet until I can find some common ground**

But as he told *Link*: “My condition does affect my work rate, but as I’ve lived with it all my life, I am used to it and just get on with things in the best way I can.”

Ben, originally from Warrington, is currently based in Swansea where he works in a lab as part of his PhD course.

He attended mainstream school, helped by an assistant, whose presence, he believes, “stopped any bullying due to my condition.”

Nevertheless Ben said: “I definitely had reduced social skills when I was younger, which were no doubt exacerbated by teenage angst.

“By the time I was studying for ‘A’ Levels I had matured in myself, although I was still very shy.

“In fact,” he went on, “I’m still very shy even now, but when I went to university I knew I had to make a concerted effort to improve my social skills.

“I still find it difficult meeting new people and I tend to be fairly quiet until I can find some common ground and I rarely talk to anyone I don’t have prior knowledge of.”

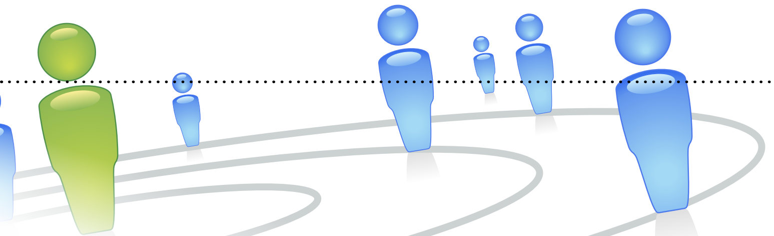
Ben said he tries to arrange any appointment or socialising for the weekend when he has plenty of time to organise himself and his thoughts.

He said: “If I am due to meet with someone at 7pm, for example, I will spend a lot of the day stressing about getting myself organised to go out after work. So I do most of my socialising at the weekend. I also try to arrange appointments for the morning when I know I am most alert.

“I often return to Warrington at the weekend to see my friends, and slowly I am getting to know people around here.”

Ben said that his ASBAH adviser, Jim Dunne, has been a huge support to him since their first meeting.

“Jim explained to me that many of the problems I experience because of my hydrocephalus are conventional, which I found incredibly reassuring.” Ben said. He also talked to me about learning procedures which help me with the things I find difficult.”



Hydrocephalus research nearing completion

A two-year ASBAH-funded research project, analysing the challenges faced by adults with hydrocephalus, is providing vital new evidence to help develop intervention strategies.

The £26,000 study, based at the Chelsea & Westminster Hospital, is examining both physical and psychological functioning in relation to everyday living.

Dr Catherine Loveday

Dr Catherine Loveday, the neuropsychologist from the University of Westminster who, along with Dr Joanna Iddon, is leading the project, said it was the most detailed study of its kind.

Detailed questionnaires were completed by 60 volunteers to find out how they feel about their own memory, language, attention, and mood, in relation to everyday living.

This same questionnaire was also completed by someone close to them so that views could be compared. In addition a sub-group were given a two-hour assessment to establish their actual skills and abilities.

Dr Loveday said: "Many adults with hydrocephalus are very articulate, which can disguise a range of difficulties they may have and often means others have unrealistic expectations of them.

"They may have very specific disabilities such as short-term memory loss, poor concentration and slow processing speed which are not obvious when they speak.

"When expectations are unrealistic, the person with hydrocephalus often feels a sense of failure. Conversely, their achievements may not reflect their true ability which again affects self-esteem.

"What we have found during our research is that once people realise that some of their difficulties are due to their condition, the relief is enormous.

"Being able to explain why they struggle to concentrate, for example, gives them back self-esteem which has a knock-on effect in helping them emotionally and socially.

"The second part of our study, which we are working on now, is producing material which will be helpful to everyone involved with hydrocephalus.

"We aim to turn all the theoretical work in this area into something which has real application and to use it to produce strategies which help in everyday life."

The project team:

Dr Catherine Loveday, Dr Jo Iddon, Neuropsychologist, **Dr Trudi Edginton,** Neuropsychologist, **Dr Richard Morgan**, Consultant Physician, Dept Therapeutics. Medical Director, Chelsea & Westminster Hospital, **Professor John Pickard,** Professor Neurosugery, Addenbrookes Hospital, Cambridge, **Ann Wing**, Continence Nurse and Clinic Co-ordinator, Chelsea and Westminster Hospital.

What the study has highlighted

The research study has initially focussed on four main areas where hydrocephalus impacts on everyday life.

The team is now working on strategies which patients can use to help overcome some of these difficulties.

Dr Loveday briefly outlined the areas and how hydrocephalus patients are affected.

Attention problems

People with hydrocephalus may have problems focussing on a task. They find it difficult to direct their attention to the right place.

At school they may have been the pupil who didn't always catch what the teacher said or hadn't absorbed what they were talking about.

This is a significant problem because it singles them out immediately and has so many implications.

Memory

An impaired memory means it isn't as good as it should be. Specific memory impairments (such as difficulty learning new information) impact on emotional and social functioning as well as causing problems in other areas.

A large part of socialising is built on shared experiences and, for someone with hydrocephalus, their memory is unlikely to be as good or as rich as other people's, although they may not be aware of this.

A person's sense of self is

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built on what they’ve done throughout their life, so poor memory impacts on this too, which again affects self-esteem and confidence.

Language & Communication

A person with hydrocephalus may be very articulate, but their comprehension is probably not as good as their production of language.

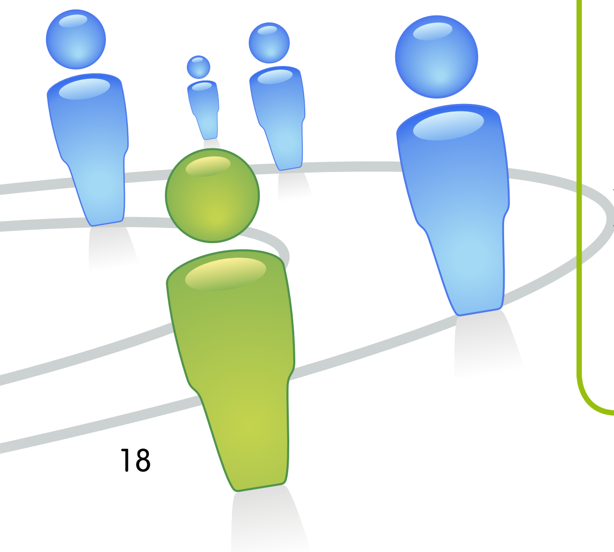
They tend to take things at face value so the use of idioms may confuse them. When people converse things are often inferred, which again leads to confusion.

Socially they can become very fixated with one small aspect of a conversation rather than looking at the bigger picture.

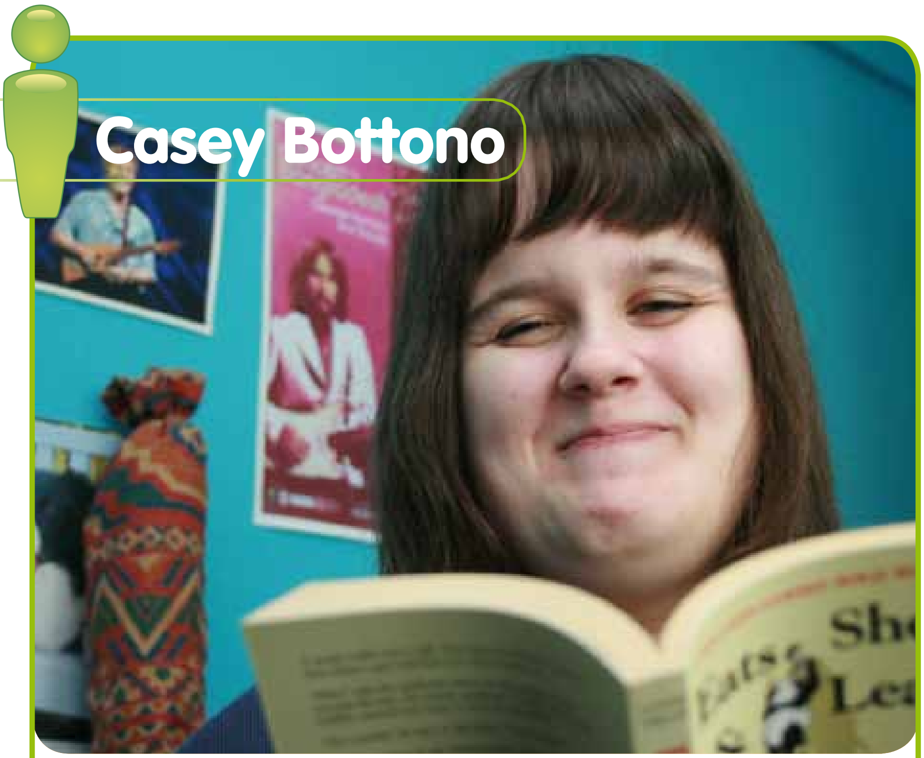
Processing speed

Their speed and ability to process information can be affected, which is particularly infuriating for someone who is otherwise bright and intelligent.

This can be a problem socially because, if they are generally articulate, others may have higher expectations. When the person with hydrocephalus is slow to grasp concepts, they are impatient and this has a negative effect on their self-confidence and self-worth.



Casey Bottono



Life without limits

“Life isn’t about limitations. I have hydrocephalus, but I choose not to be a ‘disabled person’. Instead, I have a ‘mobility problem’.

Anybody who knows me knows that I can have moments where I trip over nothing in particular, and if we’re in a restaurant, don’t ask me to carry the drinks.

In spite of that hurdle, I have a very busy social life, going out with friends on a regular basis, and am very much involved in the lives of my two younger sisters.

They’ll run rings around me, and fit in small spaces better when we play hide and seek. (You know where I am immediately- listen out for “Ow! My knees.”) I wish I could do more for them, but I think I do the best I can, considering I also have to stay upright.

I know with all disabilities people get some attention they don’t want, and don’t get some kinds that they do want.

My lack of balance can be a problem, for instance when people barge past me in shops, but unless I wear a disabled badge on my t-shirt, how will people know?

I know with all disabilities people get some attention they don’t want, and don’t get some kinds that they do want.

An example was when I started at secondary school and sports day came around - it had always been a highlight at primary school. I asked whether I could run the 100 metres. A teaching assistant asked me whether I thought I’d be making a fool of myself.

However, she was the fool when I walked the Sport Relief mile. Sure, it was more half-an-hour than four minutes - but that was an achievement for me.”

Casey Bottono, 17, student from Cornwall

Linda's line

Linda Corbett is our regular columnist. She gives her personal viewpoint on life with spina bifida

It's official – guinea pigs are cute! I am, of course, referring to the decision by Disney to make a film about guinea pigs (not before time I say) and quite naturally, as soon as the film was released, I was desperate to go and see the results of their efforts for myself.

The film was in 3D, which was an added bonus, although I spent most of the trailers trying to work out how to balance the 3D glasses on top of my ordinary glasses without dropping my chocolate macadamia ice cream on the floor.

If you didn't manage to see G Force over the summer, it's about a group of guinea pigs who have been trained by the FBI to do all sorts of special espionage work but they inadvertently get captured and taken to a pet shop, and then taken home by some less than desirable pet owners.

I feel I must point out that what happens in the film is definitely not a blueprint for how to look after a guinea pig and, if you have one at home, please do not try painting their toenails – firstly your piggy will strongly object and secondly, in the ensuing argument, may take your finger off.

Clearly there will be some children who will return from the cinema with high hopes for their cage-bound critter but without wishing to put a damper on things, they should not expect their pet to be as interactive as agents Darwin, Blaster & friends.

At the risk of creating further disappointment, your piggy will also not have the ability to download data from your (or anyone else's) computer, nor ride around in a motorised toy car.

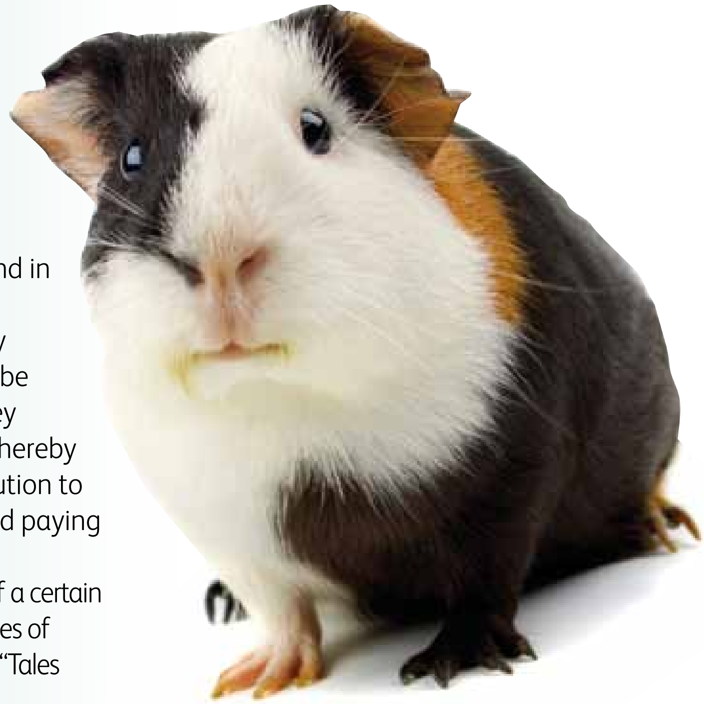
If they could, then my guinea pig Roger would be able to earn some money doing demonstrations, thereby making a useful contribution to household expenses (and paying his own vet bills).

Of course, those of us of a certain age will have fond memories of the children's programme "Tales of the Riverbank" in which the resident guinea pig (unimaginatively called GP) rode around in a Jeep or went up in an aeroplane with his furry friends.

There was none of your modern day computer generated imagery – it was all film sets and live animals, and is probably responsible for starting my lifelong love of guinea pigs. If you have no idea what I am rambling on about, type the link below into your web browser, put the sound on, sit back and enjoy:

www.youtube.com/watch?v=KUnigpl2Z80&feature=channel

Walt Disney: eat your heart out!



Obituary Faith Seward MBE

Faith Seward was born in the early 1940s with spina bifida. She attended mainstream school, gaining a place at grammar school.

Her determination and fighting spirit helped her lead the way in overcoming prejudice in all aspects of her life, but particularly in her career.

Faith gained her teaching qualification and then later, at the age of 33, she gained a BA in Education and became a deputy head at a primary school . Three years later she became the head teacher at Carr Infants School in York where she worked until her retirement in 1998.

Faith also enjoyed a busy social life, she was often found giving talks about spina bifida and her career to church groups and on local radio.

She became an after dinner speaker and swelled the funds of the Yorkshire North ASBAH by donating her fees for this. Faith was the Honorary Secretary for this local association for 40 years until its closure a few years ago.

Faith was a remarkable lady, who championed the cause for all those with spina bifida within education and her life.

She worked tirelessly to raise the issues within the York area and in 1981 was awarded an MBE for 'services to the handicapped'.

Faith died on 22nd May 2009. She is remembered fondly by those that knew her.

Fantastic fundraisers

We can help you to maximise your fundraising

As you can see from our fundraising stories there are many different ways that you can get involved with raising money for ASBAH, whether it is as an individual or a group, fundraising at your workplace or even at school.

Fundraising doesn't have to be complicated and it doesn't have to take up much time. Why not hold a who's the baby competition, where everyone brings in a photo of themselves as a baby and then charge £1 to guess the identities, or even a lunchtime quiz, a great way to get everyone together and have some fun.

Whatever you choose to do, ASBAH is on hand to help you every step of the way, with ideas and advice right through to supplying posters, sponsorship forms and other materials.

For more information and ideas about fundraising at work or school, visit our website at www.asbah.org or contact Cerys on 01733 421329 or email: cerysl@asbah.org

Treats and sweets raise funds for ASBAH

Charterhouse school in Surrey has made various kind donations to ASBAH over the years, with funds coming from numerous Mufti (non uniform) days.

Two pupils who attend the school and board at Gownboys House have decided to take their fundraising to a whole new level, by setting up their very own house tuck shop.

Adrian Tam and Ben Peck decided to set up the tuck shop, which sells a variety of tempting treats, in March this year as part of their Duke of Edinburgh's Award. They have already managed to raise £174.

To maximise sales and encourage their housemates to spend money in the tuck shop, the pair have set up a dedicated website for the shop with all proceeds being donated to ASBAH.

Adrian said: "ASBAH was our boarding house's charity before we set up the tuck shop. We thought that it was a good idea to help even more. Knowing that the money raised will aid people with conditions such as hydrocephalus and spina bifida is a great feeling."

Ben added: "We are going to keep the tuck shop going for another year and hope to raise £500 in total. We would also like to say a special thank you to our housemaster, Mr. Blatchly, for all his assistance throughout the project."

Although the tuck shop is only for members of the boy's boarding house you can visit their website to see all their hard work and check how the fundraising total is totting up at *http://gownboyscharityshop.giving.officelive.com*

Congratulations to both Ben and Adrian and thank you to Charterhouse school from all of us at ASBAH!

Powerful fundraiser by Drax

Drax Power Limited has donated £2,750 to ASBAH thanks to an innovative fundraising scheme that generates cash by rewarding good health and safety performance at the power station in Selby, Yorkshire.

The donation will benefit a range of our services including the ASBAH helpline as well as support visits by ASBAH's two advisers in Yorkshire.

ASBAH provides help to 88 families in the region of York, Selby and Goole. Currently 632 families in the whole of Yorkshire receive support on all matters relating to spina bifida and hydrocephalus.

The Drax fundraising scheme helps workers to operate safely around the plant, raising awareness for others to follow their lead. It is also a great chance to collect funds for worthwhile causes.

A grand total of £5,500 was collected, which has been divided between ASBAH and a local charity. £500 was raised for every week over a period of 10 weeks, during which accidents in the plant needed only basic first aid treatment.

ASBAH was chosen as one of the charities to receive the donation for personal reasons by a contractor who works for Drax.

Drax Power Station is the largest, cleanest and most efficient coal-fired power station in the UK. Safety procedures have to be strongly focused on, due to the large amount of people involved.

Peter Emery, production director at Drax said: "We can have around 1000 employees and contractors on site carrying out a broad range of engineering and craft skills."

£913 raised... with more still to come!

Blackburn-based Cobham Defence Communications has raised £913 so far this year to be divided between ASBAH and the Royal Blackburn Hospital's Neo-Natal Ward.

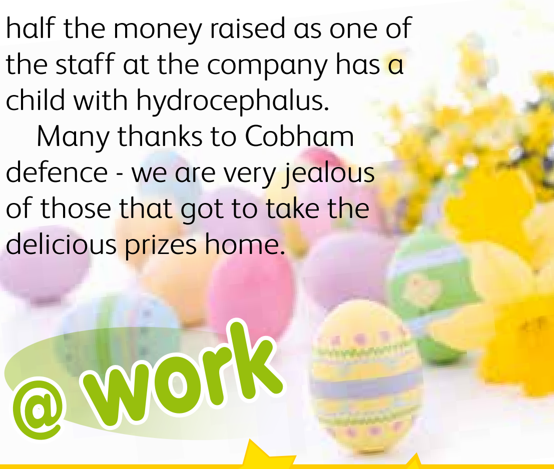
The money was raised by the company's Easter raffle with an array of chocolate goodies, as well as stuffed toys and other Easter themed prizes up for grabs.

This money will form only part of the company's kind donation as they are yet to hold their Christmas raffle, and regularly host other fundraising events which will also contribute to the grand total.

The cheque for the total funds raised will be presented to a representative of ASBAH at a Christmas buffet to be held at the company's offices.

We were chosen to receive half the money raised as one of the staff at the company has a child with hydrocephalus.

Many thanks to Cobham defence - we are very jealous of those that got to take the delicious prizes home.



Steve Attree and team raised an incredible £2,222 for ASBAH when they scaled three mountains, Snowdonia in Wales, Ben Nevis in Scotland and Scafell in the Lake District in less than 24 hours.

You can read more about these fantastic fundraisers by visiting www.asbah.org/get-involved

Veteran fundraiser John does it again!

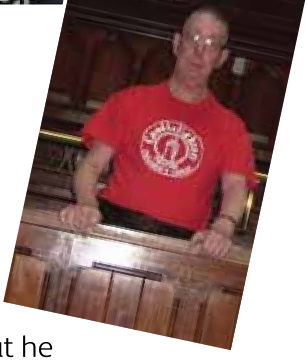
Organising fundraising events for ASBAH has become something of a pastime for John Wills from Bradford.

To-date John has successfully organised a number of sit-ins and concerts... not to mention having his head shaved and his hair dyed (although not at the same time!)

His fundraising efforts have not slowed down and his latest event, an evening of guitar music, took place on 26 June at Bradford's Idle Baptist Church and Community Centre. It was thoroughly enjoyed by all who attended.

John supports ASBAH in memory of his partner Andrea, who had spina bifida. He said: "Since the death of Andrea, I have devoted my whole life to trying to raise money. I still miss her very much, but every time I do something in her memory, it seems to draw me nearer to her."

> **I still miss Andrea very much, but every time I do something in her memory, it seems to draw me nearer to her.**



So far John has raised a magnificent £3,194 for us. Congratulations and a big thank you to John. Watch this space to see what he comes up with next!

Ted and Joan step out for ASBAH

Ted Clark, his wife Joan and family members have again completed an annual sponsored walk to raise funds for ASBAH.

For many years the couple have organised and taken part in the Mayor's Walk in their home town of Leamington Spa.

Ted, Joan and members of their family have walked the two-and-a-half mile circuit more times than they can remember. People taking part in the walk can complete the circuit as many times as they can stand within a four- hour time period!

Ted, who is the chairman of the Mayor's walk, and Joan raise money for ASBAH in memory of their son Andrew who had spina bifida.

Their friend Ian Locke, who worked with Ted at Warwickshire College for 20 years, also takes part in the walk.

Together, Ted and Joan have so far raised over £6000 for ASBAH.

Many thanks to Ted, Joan and all their friends and family for their tremendous support!

Mike Smith and friends from Lymm in Cheshire have raised a towering £4,641 for ASBAH by completing the Three Peaks Challenge, a course of climbs that sees participants scaling the UK's three tallest mountains in less than 24 hours.

Fundraising doesn't always mean slogging up a mountain or dragging yourself 26 miles to complete a marathon; it can be a glamorous affair too! The Dans Satam Belly Dance Group raised £375 for ASBAH through an evening of belly dancing and Arabian dance.

Schools lead the way in fundraising for ASBAH

You may remember Shaun Smith from the last edition of *Link*. At Easter Shaun very bravely donned a Benny Bear costume, especially shipped all the way from China, to walk 12 miles from near Burnley to Blackburn with friends and family to raise over £3,000 for us.

When *Link* spoke to Shaun he was keen to thank everyone who came along on the day and got involved. Not content with praising his fellow walkers, Shaun was also enthusiastic to highlight the additional support he and his family had received from his children's schools.

St Andrew's primary school and Rhyddings Business and Enterprise school, both in Oswaldtwistle, have been invaluable in providing support to the family since Shaun's youngest son, Harrison, was diagnosed with hydrochephalus.

The two schools have also contributed by raising funds for ASBAH. Children from Rhyddings Business and Enterprsie School took part in the sponsored walk, arranged by Shaun's wife, Dawn, as well as other charitable events such as a cake and bake sale and a summer fair, organised as part of the school's own charity club 'Interact'. So far £670 has been received!

St Andrew's school also raised funds by hosting non-uniform days for their pupils. To-date £170 has been raised with plans to hold similar events in the future.

> **It is really great to have such wonderful support from the children's schools.**

Shaun said: "It is really great to have such wonderful support from the children's schools. It is fantastic to see everyone rallying around. I'm sure there will be more fundraising in the future as the children really seem to enjoy taking part and raising money for very worthy causes such as ASBAH."

Thank you to all pupils and teachers at both schools and to Shaun, Dawn and family for their ongoing fundraising efforts.

A terrific triathlon

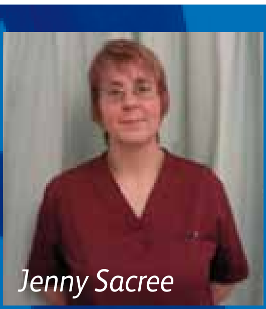
Completing a triathlon in one hour and 32 minutes deserves a pat on the back – this goes to Neil King from Harpenden who competed in the Mazda Blenheim Triathlon on Saturday 6 June in Woodstock, in aid of ASBAH.

Neil was joined by his colleague Cressida Hogg. They raised money for ASBAH as their colleague and friend, Jim Stoner, whose daughter has spina bifida, has received a great deal of support from us.

When asked what the highlight of the event was, Neil said: "I did a lot of training for the triathlon. I had three objectives: one, not to come last, two, not to walk during the run and three to lose lots of weight. I am pleased to say I achieved all three!"

Neil and Cressida raised a fantastic total of £11,682 through individual sponsorship and generous matched funding from their company 3i.

Codman - Working in partnership with ASBAH



Jenny Sacree

"The job can be challenging but it is enjoyable. Seeing someone's condition improve is incredibly rewarding and because I tend to see patients at most of their appointments, I can build up good relationships with them."

Meet Jenny Sacree, the hydrocephalus neurosurgical nurse practitioner at Bristol's Frenchay Hospital.

Many hydrocephalus patients attending Bristol Frenchay's neurosurgery department will recognise Jenny Sacree, the dedicated hydrocephalus nurse practitioner.

Her calm yet confident manner coupled with more than two decades knowledge and experience makes her a reassuring figure both on the wards and in the regular clinics.

Although Jenny gained most of her experience working in paediatrics, since taking over the post 18 months ago her workload is split 50:50 between adults and children.

When *Link* asked her to describe a routine day she laughed, "No day is the same, which is part of the reason I find my role so enjoyable.

"My days obviously have a structure to them, starting with my 7.30am paediatric ward round and the regular clinics, but I see many different patients with varying needs all day long.

"Patients also have my bleep number so they can call and talk to me about any concerns they may have. They find it very reassuring to leave the hospital knowing that I'm only a call away."

We are one of the few centres in the country to have a dedicated Normal Pressure Hydrocephalus service

The department runs several hydrocephalus clinics both on-site and on an outreach basis in Plymouth.

And although Jenny's first love has always been paediatrics, she says she gains a great deal of satisfaction from her work with adults, in particular patients with Normal Pressure Hydrocephalus.

"We are one of the few centres in the country to have a dedicated Normal Pressure Hydrocephalus (NPH) service," she explained. "It is an excellent service and the work is highly rewarding because the results are so good.

"I often see people who are in wheelchairs and have been unwell for a long time. Once we diagnose NPH and treat them they usually respond very quickly and it is thrilling to see the patient improve and regain a good quality of life.

"We have shunted many patients who are in their 70s and 80s, and even two who have been over 90 and most have responded well to their treatment.

"When I took up my post I hadn't worked with elderly patients since doing my training and I have been surprised at how much I've enjoyed this part of the job. They are a fabulous group of people and it is a very satisfying and rewarding area of neurosurgery."

Jenny works under the leadership of three paediatric consultant surgeons – Mr Ian Pople, Mr Richard Edwards and Mr Michael Carter. The team includes three neurosurgery registrars.

The unit is one of the few centres to provide infusion study tests, which can identify NPH and problems in shunted and ventriculostomy patients.

Jenny said: “The procedure is relatively quick, taking around 1 hour 20 minutes and can be done on a day care patient basis.

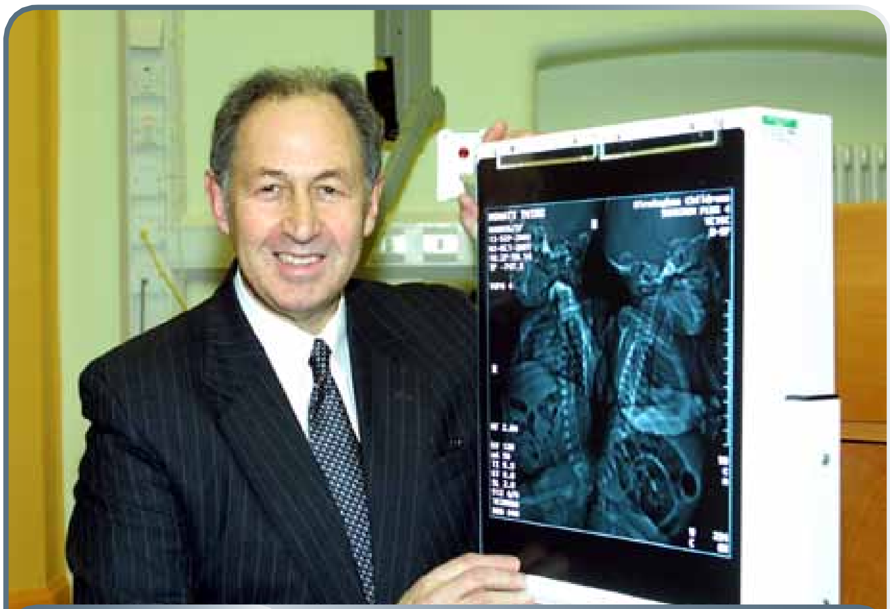
“We’ve offered the procedure here for more than three years and it is very successful in determining what the problem is. If we detect a blocked shunt, for example, the patient can be admitted and operated on very quickly.”

It’s a demanding role and Jenny works long hours - 7.30am – 5 pm Monday to Friday – but she enjoys the vital part she plays at Frenchay.

“The job can be challenging but it is enjoyable. Seeing someone’s condition improve is incredibly rewarding and because I tend to see patients at most of their appointments, I can build up good relationships with them. I really feel that we provide an excellent service here.”

KEY POINT

- **Jenny Sacree talks about her job at Bristol’s Frenchay Hospital**
- **Tony Hockley obituary**



Obituary Tony Hockley

We were very sad to learn of the death of Tony Hockley from a heart attack at his home in Birmingham on 30 June 2009.

Mr Hockley, who retired from his post as Paediatric Neurosurgeon at Birmingham Children’s Hospital three years ago, had been a member of the Society for Research into Hydrocephalus and Spina Bifida for more than 30 years.

Tributes have been paid by his colleagues who described him as a man of “tremendous warmth and kindness” and from parents of the many children with spina bifida and hydrocephalus that he treated.

He trained at the London Hospital and, after working as a registrar in neurosurgery in Cambridge and Toronto, he was appointed Consultant Neurosurgeon to the Queen Elizabeth and Children’s Hospitals in Birmingham in 1978.

In 1989 Mr Hockley was the founding chairman of the British Paediatric Neurosurgical Group.

He leaves a wife, Heather, and three sons.

hydrocephalus action

ASBAH is working in partnership with Codman to promote ‘Hydrocephalus Action’, a campaign aimed at raising the awareness of hydrocephalus through many channels and events.

This campaign aims to increase the level of understanding amongst the general public, healthcare professionals and public policy decision makers throughout the UK. Look out for news and further information on the website.

ASBAH families involved in market resea

ASBAH families took part in market research earlier in the year to give their views on how spina bifida affects their day-to-day lives and to give their opinions on continence products.

The market research sessions were set up by Coloplast, a worldwide supplier of continence products, as part of an initiative to make more information about spina bifida widely available.

The project kicked off in January when its marketing team got together with ASBAH staff to explain its aims.

Coloplast's Peristeen Business Unit Manager Jane Fox said: "We are developing our range of material on spina bifida to increase awareness of the condition and to educate about continence issues.

"It is a large project because it includes everything from product guides, downloadable information on our website and brochures aimed at a wide cross-section of people from healthcare professionals and individuals to families.

"We felt it was vital that we spoke to both ASBAH and to the people who actually use continence products before starting out.

"At Coloplast we try never to make any assumptions about our customers needs. Part of our mission statement is keeping close to our customers and listening carefully to what they say."

After providing medical and practical information, ASBAH contacted families to find individuals or parents who would be happy to take part in the market research.

"We were overwhelmed by the response," Jane added. "So many people came forward keen to share their experiences."

Coloplast brought more than 14 ASBAH families to their Peterborough offices to talk about all aspects of spina bifida and continence issues

Jane added: "The information we gained was invaluable. Everyone here learned so much. Without talking to those who use continence products we cannot understand their level of needs or their concerns."

Key points

- **Coloplast talks to customers about their continence needs**
- **More information about spina bifida on Coloplast website**
- **Educational brochures for healthcare professionals**

Coloplast

Coloplast and ASBAH are working in partnership to campaign for an increased awareness of bladder and bowel health and to support ASBAH's members and families in their efforts to live a full and satisfying life.

"I found the meeting to be very informative and I think it gave everyone real insight into how people who aren't familiar with continence issues view the subject.

We were asked to look at a variety of proposed publicity material for use in GP surgeries, clinics and magazines and then say whether we thought they were suitable - and if we were comfortable with the message they were putting across.

"I felt that our input was valued and Coloplast were very interested in our thoughts and ideas."

Caroline Toombes

Experts say cranberry juice does reduce UTIs

Medical experts are continuing to recommend drinking cranberry juice to reduce urinary tract infections (UTIs) despite reports in the national press which queried its effectiveness.

According to the reports, the European Food Standards Agency (EFSA) has rejected the health benefit claims of a number of brands, including Ocean Spray.

For several years medical experts around the world have believed cranberry juice reduces UTIs by stopping bugs (especially E coli) from sticking to the bladder wall. ASBAH has long advised people with spina bifida to drink it. However, people taking Warfarin or other blood thinners have always been advised **not** to drink it or take the capsules.

Jared Konstanty, Managing Director of Ocean Spray Europe, Middle East and Africa, said the confusion has arisen because recent clinical studies, voluntarily submitted to the EFSA, in support of this specific health claim were not conducted in the manner that EFSA demands

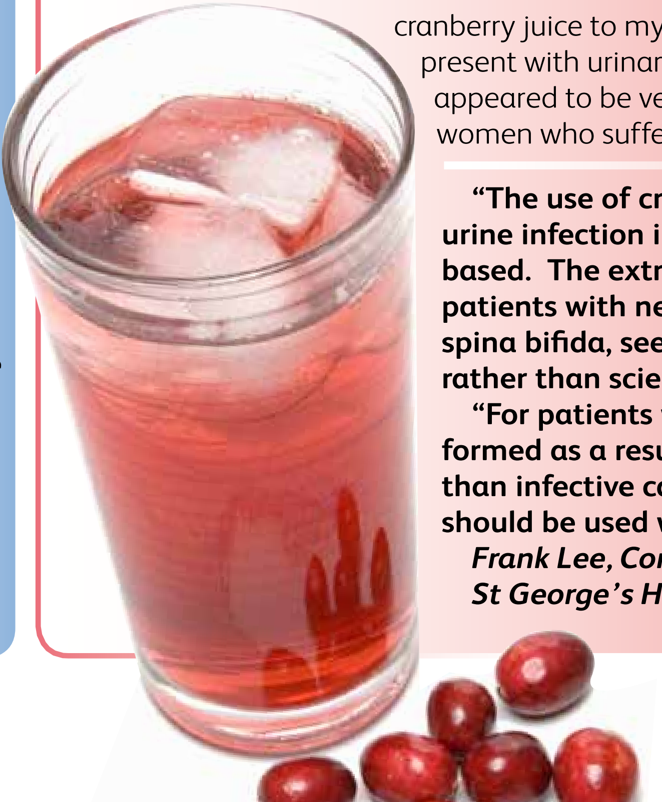
He added: "Decades of research from around the world, from independent bodies, confirm that regular consumption of cranberry juice helps prevent urinary tract infections. This is not in dispute, even by EFSA.

"EFSA did not censure Ocean Spray or state that Ocean Spray was making false claims. The total EFSA opinion supported our claims that Regular Consumption of Cranberry Classic helps prevent recurrent UTIs.

"Ocean Spray has never made a false health claim and we never will. Medics and health professionals from around the globe have come out in support of cranberry."

Dr Rosemary Leonard, MBE, GP and broadcaster said: "There is good evidence that cranberry juice stops bacteria from sticking to the lining of the urinary tract. The research work done so far has shown promising results but stringent requirements of the EFSA mean that more clinical trials need to be done."

"But as a GP I have no hesitation in recommending cranberry juice to my female patients that present with urinary tract infections and it has appeared to be very helpful, particularly in women who suffer with recurrent cystitis."



"The use of cranberry juice to reduce urine infection in women is evidence-based. The extrapolation of its use in patients with neurogenic bladder, e.g. spina bifida, seems reasonable on clinical, rather than scientific, grounds.

"For patients with kidney stones formed as a result of metabolic, rather than infective causes, cranberry juice should be used with caution."

Frank Lee, Consultant Urologist, St George's Hospital, London.

Get the most out of Your Voice

Many of our readers are keen Your Voice (YV) members and we're keen to encourage more of you to sign up.

YV, ASBAH's adult group, was set up in May 1992 to give adults with spina bifida or hydrocephalus the chance to play an active role in the development of ASBAH's policies.

Since then the group has developed into a lively social network and many people have formed strong friendships by getting involved.

YV organises regular meetings and fun events, at different venues around the country, where a wide range of practical activities, training, and new experiences will broaden your life.

As a member you'll also receive copies of the YV newsletter.

Mark Harris,YV Development Officer, said: "I would encourage people to join YV to gain further independence, give them more confidence and learn new skills.

"It is also a good opportunity to meet new people with similar issues, make new friends and participate in a forum on the YV website"

Our YV website

YV's own dedicated website enables members to interact with others through the popular forum facility.

Signing up to the forum gives you the chance to have your voice heard on matters important to you and it's a great way to make new friends.

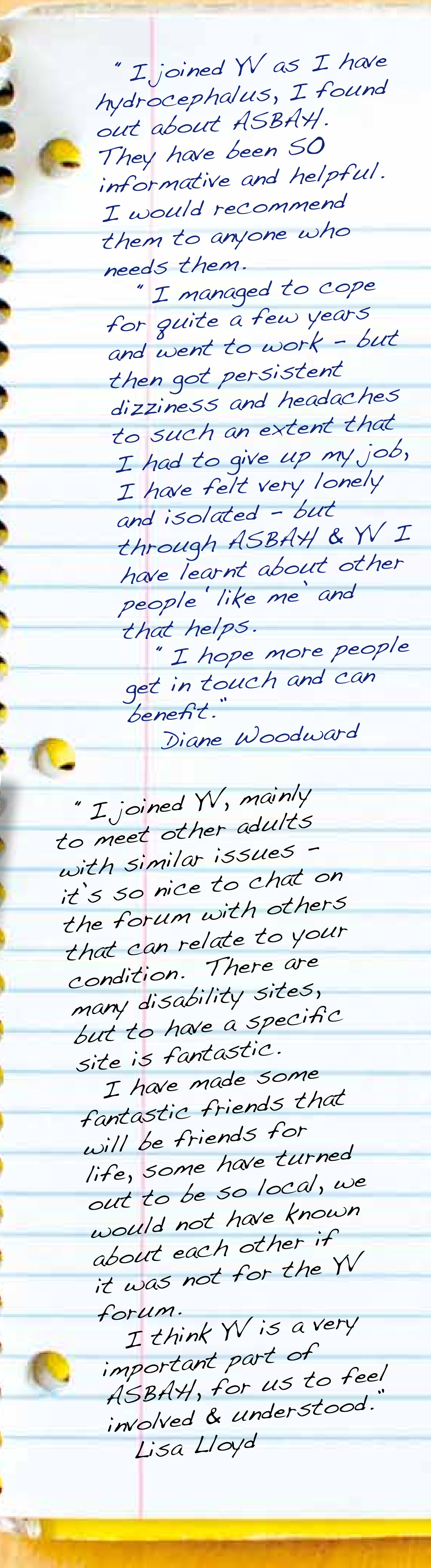
Membership also gives you access to regular news and information, keeping you informed of YV activities.

To access the forums you must be a registered YV member, over 18-years-old and have spina bifida or hydrocephalus.

To register for the forum online go to www.yourvoicegroup.org and go to the 'How to join YV' page.

If you're new to online forums it may appear a little daunting at first... but don't be put off. It's easier than it looks.

Mark Harris is the Your Voice Development Officer and YV members can contact him by calling 01733 421322 or email him at: markh@asbah.org



"I joined YV as I have hydrocephalus, I found out about ASBAH. They have been SO informative and helpful. I would recommend them to anyone who needs them.

"I managed to cope for quite a few years and went to work – but then got persistent dizziness and headaches to such an extent that I had to give up my job, I have felt very lonely and isolated – but through ASBAH & YV I have learnt about other people 'like me' and that helps.

"I hope more people get in touch and can benefit."

Diane Woodward

"I joined YV, mainly to meet other adults with similar issues – it's so nice to chat on the forum with others that can relate to your condition. There are many disability sites, but to have a specific site is fantastic.

I have made some fantastic friends that will be friends for life, some have turned out to be so local, we would not have known about each other if it was not for the YV forum.

I think YV is a very important part of ASBAH, for us to feel involved & understood."

Lisa Lloyd

"I joined the group to get to know other adults who had experience of living with SB. I have learned that by sharing life experience it helps yourself and others to overcome different situations.

When I was younger my parents had little or no support. Unfortunately they were not aware of the existence of ASBAH. I believe the more people are made aware of organisations like ASBAH the better understanding there will be of such disabilities.

YV is a good vehicle to raise awareness. Having a social work background I was able to share information with others which proved useful.

Keith Collins

"YV is an excellent way to meet other people with similar problems and choices for both serious issues and fun! The YV weekend that I went on was a fantastic event and a learning curve for many participants. It was great fun and a social outlet providing a safe environment for those who may not be used to being away from their family, thus promoting independence."

Liz Potts

"I would never have had the confidence to join YV. My mum found out about the first conference and talked me into going with my PA.

I am now gutted if I miss one. Joining has helped my confidence – in particular, being socially confident.

I hardly ever mixed with other disabled people, when I was younger. I went to mainstream school, before going to a college for disabled people. To my shame, I was always a little uncomfortable with the concept of what I used to call 'special' holidays.

Now I realise that these events are a chance to share stories and experiences with people who know what your life is like and know exactly where you're coming from.

I'd like to thank ASBAH for the weekends. There is no way many of us could stay in such accessible, helpful and welcoming hotels, and enjoy such comfort without paying a lot more than we do.

Bonnie Harris

Your Voice presents

Looking Good Feeling Great

Book NOW

Date:

Friday 30th October to Sunday 1st November 2009

Venue: Jury's Inn, Brighton, East Sussex

Cost:

Weekend: £110 - includes accommodation, workshops and meals

Day (Saturday 31st only): £35 - includes workshops and lunch

Sessions on:

- Positive Thinking
- Confidence Building
- Independent Living
- Relationships
- Fashion
- Body Shop/ Aromatherapy
- Exercise and Nutrition

More information:

For further information and to register your interest contact:

Mark Harris
ASBAH House
42 Park Road
Peterborough PE1 2UQ

Telephone: 01733 421322
Email: markh@asbah.org

The delegate rate is being subsidised by Your Voice

News from ASBAH managers around the country

ASBAH in the North of England & West – from Joan Pheasant, Regional Manager

The Northern Region is in a state of change as we have grown in size (geographically) since we welcomed Midlands' advisers, Geraldine Long and Jenny Green, to the region.

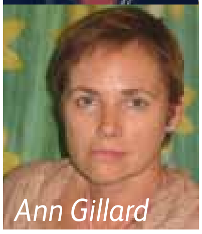
The name of the region has been changed to: North of England & West Midlands Region (NEWMO).

We bid farewell to Bernadette Baldwin as she set off to do an MSc in Psychological Approaches to Health, at Leeds University. This is full-time for one year. We have looked at re-organising the staff in the region and are advertising for a 17.5-hour post.

The Region is holding a Family Day at the National Coal Mining Museum, in Wakefield, on 31st October. This will be for families with children/young people still attending school. There will be groups for parents to attend and activities for the children which will include crafts and soap making, visits to the see the pit ponies and tours down the mine.

ASBAH in London and the South Region – from Jo Francis Regional Manager


Lynne Young


Ann Gillard

The region has been expanded to take in the West Country and is now known as the London and South Region. I would like to welcome Lynne Young and Ann Gillard to the team.

Gill Yaz is now full time Health Adviser and part of her role is to develop contacts with hospitals and clinics in the region.


Gill Yaz

The London part of the region is being re-organised and in October we hope to appoint an adviser for North West London to replace this part of Gill Yaz's role.

We will also be appointing an adviser to replace Belinda Williams and Emma McKeever who both left earlier in the year. The new 28- hour post will cover Berkshire, Hampshire, Dorset and the Isle of Wight.

ASBAH in the East – from David Isom, Regional Manager

Eastern Region will be hosting its next Local Association Forum Meeting on Saturday 17 October. We are delighted that Jackie Bland will be the guest speaker on this occasion.


Jackie Bland

The meeting will take place at ASBAH House from 11am. A buffet lunch will be available for everybody who attends and parking is free. Everyone is welcome, so please come along!

ASBAH in Wales

Kate Thomas started as Wales Director on 1st September with Elin Ifan retiring on 11th September.

Elin thanked all those who have made working for ASBAH a pleasure over the last 25 years and sends her very best wishes to Kate in her new role.


Kate Thomas

ASBAH in Northern Ireland – from Cathy McKillop, Director

Catherine McCurry, ASBAH's Northern Ireland Education Adviser, has raised £900 by doing a sponsored swim. Catherine swam 50 lengths of the pool on seven consecutive days. Congratulations Catherine!

Derry/Londonderry parents group: This group was established by Marie McGonnell and has now met on three occasions.

Belfast 18-30 group: We hope to start a group for 18 – 30 year-olds in the Belfast area. The initial date for meeting is the 10 October and on that day we hope to explore opportunities for the future of such a group.

Lloyds TSB Foundation gave a grant of £3,000 towards funding for the Northern Ireland Education Adviser post.


Cathy McKillop (left) receives the Lloyds TSB Foundation grant

Diary dates

Contact your regional office for further information on any of the events below

Dunstable Support Group

For people with spina bifida and/ or hydrocephalus and their carers.
Meets: 1–3pm, usually on the second Monday of each month.
Where: Disability Resource Centre, Poynters Road. Dunstable.
Dates for 2009/2010:
9 Nov 14 Dec 10 Jan
Please come whenever you can. While there is no crèche, young children are always welcome.
Contact: Valerie Bottoms on 01582 757745

Northern Region: York Drop-in 2009

Where: Low Moor Community Centre, Bray Road, Fulford, York YO10 4JG.
When: Second Wednesday each month:
11 Nov 9 Dec
Time: 10.15am – 12 noon.
For further information please contact the NEWMO office on 0113 255 6767 or email *nro@asbah.org*

Eastern Region Forum

Date: Saturday 17 October 2009
For further details please ring 01733 421309.

Suffolk / Norfolk Spina Bifida / Hydrocephalus Support Group

This group for adults with spina bifida and/or hydrocephalus and their carers meets every two months. Parents of teenagers with spina bifida and/or hydrocephalus are also very welcome. There is ample parking and disabled access at the hall. Do come and join us for tea/ coffee and a chat. Area adviser Val Meyer-Hall attends meetings whenever possible

Where: Roydon Village Hall,
High Road, Roydon,
Nr Diss, Norfolk.

10.30am-12.30 on the following dates for 2009/2010:
5 Nov 7 Jan 4 March
For further details please contact Margaret & Alan Twyford on 01728 860916 or by email ***twyfords@aandmtwyford.plus.com***

Family Day

Where: National Coal Mining Museum, Wakefield
When: 31st October 2009
Time: 10am - 3.30pm
Cost: £6 per adult Children Free
For further information please ring NEWMO Office on 0113 255 6767 or email *nro@asbah.org*

Your Voice is hosting a 'Looking good, feeling great' event. Friday 30 Oct - Sunday 1 Nov 2009 at Jury's Inn in Brighton. More information contact Mark Harris, Your Voice Development Manager on 01733 421322 or email ***markh@asbah.org***

ASBAH will be having a stand at ENABLE 09 on 6 & 7 November, at the Ricoh Arena, Coventry and also at Kidz Up North at the Reebok Stadium, Bolton. Thursday, 26th November 09.

Please contact the editor (Link@asbah.org) with dates of your events for the next issue of Link by Friday 27 November 2009.

Regional contacts

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Fax: 01733 555985
Email: *ero@asbah.org*

London and South
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EN4 8SB
Tel: 020 84490475
Fax: 020 84406168
Email: *sero@asbah.org*

ASBAH in Wales / ASBAH yng Nghymru
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Email: *wro@asbah.org*

ASBAH N. Ireland
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Tel: 0845 450 7755
Email: *niro@asbah.org*

*For details of Local Associations contact your regional office or ASBAH Helpline or visit **www.asbah.org***

Holiday lets

For classified rates, please contact the *Link* Editor.
Email: *link@asbah.org*

ISLE OF WIGHT ASBAH - HOLIDAY BUNGALOW

Wheelchair-accessible bungalow, sleeps six. Open-plan lounge/kitchen, wetroom. Site facilities. Local heated accessible pool. Beautiful area. Transport advisable. **Details and rates: Sylvia Griffiths, 3 Western Road, Shanklin, Isle of Wight PO37 7NF Tel: 01983 863658** ***www.iwasbah.co.uk***

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Email: *irene@sundancevillas.co.uk*
www.sundancevillas.co.uk

ASBAH Helpline
0845 450 7755

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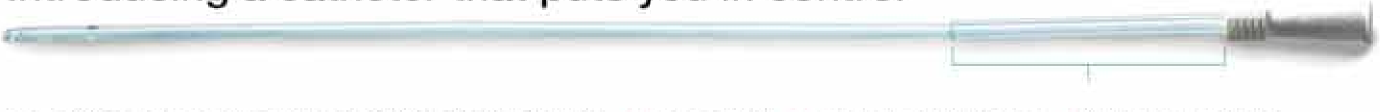

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To receive a FREE sample of **Speedicath** Control, fill in this coupon and return it to: Coloplast Ltd, First Floor, Nene Hall, Peterborough Business park, Lynchwood, Peterborough, PE2 6FX

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I understand that Coloplast will keep the necessary personal information on its database and I may ask to see this information. Coloplast will not disclose this information to a third party. If you do not want Coloplast to keep you updated with relevant information on products and services, please tick this box ☐

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